



## Long-Term Quality of Life After Living Kidney Donation

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### ABSTRACT

**Background.** The supply of deceased donor kidneys available for transplantation is not sufficient to meet the demand. Despite a low rate of complications for donors and superior outcomes for recipients, living kidney donation (LKD) is on the decline for reasons that remain unclear.

**Methods.** We performed a retrospective review and analysis of living kidney donors (LDs) who underwent donor nephrectomy between January 1, 2000 and December 31, 2010. Candidates who were excluded from LKD were identified as control subjects (CSs). LDs and CSs were invited to voluntarily undergo a quality of life assessment using Short Form 12 v1.0 Questionnaire (SF-12) and an addendum questionnaire (AQ). The SF-12 and AQ were administered by telephone. Statistical analysis of the results was performed to obtain the SF-12 physical component score (PCS), SF-12 mental component score (MCS), and the AQ score. PCS and MCS for the general population were obtained from the 1998 National Survey of Functional Health Status.

**Results.** During the study period, 83 LDs and 116 CSs were interviewed. LDs were noted to have higher PCS (54.1 vs 49.6) and MCS (55.7 vs 49.4) compared with the general population. Ninety-nine percent of LDs believed that their quality of life did not decrease after LKD; 21.7% reported experiencing complications. Half of the LDs (48%) reported missing 1 day of work for evaluation; 71% of LDs reported missing at least 4 weeks of work after LKD. Nearly all LDs (99%) would undergo donation again. Fifty-two percent of LDs reported adhering to the recommended 2-year follow-up schedule with the transplantation team; 87% of LDs reported seeing their primary care physician.

**Conclusion.** LDs are physically and mentally healthier after LKD compared to the general population. Most donors miss at least 1 month of work for LKD and undergo some form of post-donation monitoring. Despite this commitment, LKD is a very satisfying experience.

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**F**OR individuals suffering from end-stage renal disease (ESRD), the benefits of renal transplantation are well established. Renal transplantation confers improved survival, a better quality of life (QOL), and decreased healthcare costs.<sup>1-5</sup>

Presently, the number of deceased donor kidneys is vastly inadequate to supply an ever-increasing number of patients who would benefit from renal transplantation.<sup>6</sup> There are more than 94,000 renal transplantation candidates on the waiting list; half of them will wait more than 2 years to receive a deceased donor organ. Furthermore, in 2009, 6.3% of these candidates died awaiting a kidney transplantation.<sup>6</sup> In an effort to meet this increase, numerous

strategies have been used to maximize the use of deceased donor kidneys, such as the use of extended-criteria donor kidneys and Center for Disease Control high-risk kidneys.<sup>7-9</sup> Nevertheless, the demand continues to exceed the supply.

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Living kidney donation (LKD) provides an alternative source of kidneys for transplantation. Although LKD has shown superior outcomes for the recipient, the annual donation rate has not increased to meet the demand. Between 2001 and 2011, the LKD rate peaked at 6647 donations/year in 2004, and decreased to 5770 donations/year in 2011.<sup>6</sup> The reason for this trend is unclear.

Although individual center data provides useful insight into the risks and benefits of the donation procedure, the QOL of living kidney donors (LDs) in the United States remains to be well established.<sup>10,11</sup> Potential LDs have access to a variety of sources when considering LKD, including the internet, social networks, and support groups. The quality and wide applicability of this data is variable; it may not address misconceptions about organ donation, and it may even dissuade potential LDs from participating.<sup>12,13</sup>

The purpose of this study was to assess the QOL of LDs in the United States. Specifically, our aim was to define the impact of the preoperative donor evaluation, donor nephrectomy, surgical recovery, and the postoperative monitoring on the life of the donor. The authors hypothesize that the LD QOL is comparable before and after LKD.

## METHODS

We performed a cross-sectional cohort study of LDs who underwent LKD at Albany Medical Center. Patients were identified by retrospective review of the Albany Medical Center renal transplantation database. LDs aged 18 to 60 years who underwent donation between January 1, 2000 and December 31, 2010 were invited to participate in the study. The control subjects (CSs) were patients who were evaluated for kidney donation, but who were excluded due to a positive crossmatch, medical contraindications discovered during testing, or personal reasons. Data collected from chart review included age, ethnicity, sex, body mass index (BMI; kg/m<sup>2</sup>), serum creatinine level (mg/dL), and the time spent out of work before and after LKD.

The QOL of CSs and LDs was quantified using the Short Form 12 v1.0 Questionnaire (SF-12), which was administered by a single investigator during a telephone interview.<sup>14</sup> The physical component score (PCS) and mental component score (MCS) from the SF-12 were compared to those obtained from the 1998 National Survey of Functional Health Status.<sup>15</sup> Additionally, an addendum questionnaire (AQ) was administered to LDs after the SF-12 questionnaire.

All scoring and statistical analysis was performed using SAS software version 9.3 from SAS Institute Inc., Cary, North Carolina.

## RESULTS

Upon review of the renal transplantation database, 332 CSs and 227 LDs were identified. Of these, 116 CSs and 83 LDs agreed to participate in the study. Demographic data of the LDs are reported in Table 1. Statistical analysis showed no significant correlation between age, BMI, creatinine level, and the PCS. Statistical analysis showed no significant correlation between age, BMI, creatinine level, and the MCS. The BMI was unable to be recovered for LDs who underwent LKD before 2005 (n = 31; 37%).

**Table 1. Living Kidney Donor Demographics**

Demographic	n = 83
Sex	
Male (%)	26 (31)
Female (%)	57 (69)
Ethnicity	
White (%)	80 (96)
Other (%)	3 (4)
Mean age (y)	42.8
Mean BMI (kg/m <sup>2</sup> )	26.3
Mean creatinine (mg/dL)	0.88

Abbreviation: BMI, body mass index.

LDs were found to have a higher PCS (54.1 vs 49.6) and MCS (55.7 vs 49.4) compared to the general population. CSs were also noted to have higher PCS (52.2 vs 49.6) and MCS (56.3 vs 49.4) compared to the general population. These results are summarized in Table 2.

Self-reported complications were experienced by 21.7% of LDs. These complications included postoperative pain, chyle leak, medication allergy, wound site sensitivity, and wound infection. All reported complications are listed in Table 3. Despite these reports, the scored AQ showed that 98.8% of LDs believed that their QOL did not decrease as a result of undergoing LKD.

“Time commitment” was defined as the amount of time that a donor spent out of work to undergo evaluation, donation, recovery, and post-donation monitoring. Nearly half of the LDs (48%) missed 1 day of work for preoperative evaluation; 71% of LDs missed at least 4 weeks of work for recovery from LKD. When LDs were asked if they would repeat their decision to undergo donation, 99% answered in the affirmative.

During the first donor evaluation, our program recommended post-donation monitoring by the transplantation team for 2 years after donation, and annually thereafter by a primary care physician. After LKD, approximately half (52%) of the LDs completed the recommended 2-year monitoring regimen, whereas 86% of LDs visited their primary care physician to be evaluated. The AQ and its responses can be found in Tables 4 and 5.

## DISCUSSION

The authors conclude that LKD does not decrease QOL for LDs. Not surprisingly, in many cases, it leads to improved physical and/or emotional well-being. Our results suggest that LDs are physically and mentally healthier than the

**Table 2. SF-12 Scores of Control Subjects, Living Kidney Donors, and the General Population**

Population	Average PCS	Average MCS
Control subjects	52.2 +/- 6.2	56.3 +/- 5.0
Living kidney donors	54.1 +/- 5.9	55.7 +/- 5.7
General population	49.5 +/- 9.9	49.4 +/- 9.8

Abbreviations: PCS, physical component score; MCS, mental component score.

**Table 3. Complications of Living Kidney Donation by Patient Report**

Complication type	n = 17
Pneumothorax (%)	1 (5.9)
Bleeding (%)	1 (5.9)
Ileus > 5 days after nephrectomy (%)	1 (5.9)
Wound infection (%)	1 (5.9)
Chronic pain, resolved (%)	4 (23.3)
Pulmonary embolism (%)	1 (5.9)
Incisional hernia (%)	1 (5.9)
Chyle leak (%)	1 (5.9)
Renal insufficiency (%)	1 (5.9)
Abnormal liver enzymes (%)	1 (5.9)
Medication allergy (%)	1 (5.9)
Dehydration (%)	1 (5.9)
Constipation (%)	1 (5.9)
Unspecified (%)	1 (5.9)

general population. There are several reasons for this finding. First, although there are no universal qualifying criteria for LDs, like most transplantation programs, we use a screening protocol to ensure that LDs are free of uncontrolled hypertension, obesity, diabetes, cancer, kidney disease, and heart disease. Pre-donation screening is intended to eliminate individuals who are potentially not healthy enough to undergo donation. This screening process selects the healthiest patients from the general population. Second, by undergoing a major medical procedure and subsequent physician visits, LDs may receive additional preventive medical care.<sup>16</sup> Close protocol surveillance of LDs may serve to motivate these patients to follow a healthy diet and exercise regimen, both of which contribute to improved general health.<sup>17</sup> Similar effects have been noted in other studies in which improved self-esteem and higher

**Table 4. Living Donor Quality-of-Life-Related Questions From Addendum Questionnaire**

Question	Yes (n = 83)	No (n = 83)
Were there other circumstances separate from the donation experience that affected your life negatively? (%)	12 (14)	71 (86)
Do you feel that your quality of life decreased as a result of your donation? (%)	1 (1)	82 (99)
Did you experience any complications during the healing process? (%)	18 (22)	65 (78)
Given the option to repeat your decision, would you still undergo living kidney donation? (%)	82 (99)	1 (1)
Did you undergo regular follow-up for 2 years after donation with the transplant team? (%)	43 (52)	40 (48)
Do you continue to undergo annual follow-up with your medical doctor? (%)	71 (86)	12 (14)

**Table 5. Living Donation Time Commitment**

Variable	Living Donor (n = 83)
Work missed before surgery	
1 d (%)	39 (47)
2 d (%)	13 (16)
3 d (%)	9 (11)
4 d (%)	5 (6)
5+ d (%)	15 (18)
Unemployed (%)	2 (2)
Work missed after surgery	
1 wk (%)	6 (7)
2 wk (%)	8 (9)
3 wk (%)	10 (12)
4+ wk (%)	58 (70)
Unemployed (%)	2 (2)

overall QOL were noted after donation.<sup>18,19</sup> The high level of physical and mental health observed in the participants of this study is consistent with other studies of organ donor QOL from the United States and abroad.<sup>20,21</sup>

To promote LKD, it is essential to identify factors that deter potential donors from pursuing LKD. Fear of surgical complications has been reported as a primary deterrent from organ donation.<sup>22</sup> However, our study suggests that donors and surgeons define “complications” differently. What surgeons may consider as part of the normal recovery process (eg, incisional pain), potential donors may perceive as a complication. According to the AQ, 21.7% of LDs reported “complications” of surgery. For example, from the surgeon perspective, few conditions reported in Table 3 would be considered true surgical complications. However, for prospective donors, concerns, such as incisional pain, may be unacceptable as part of the recovery process. We postulate that the donor’s perceived complication rate is far higher than the surgeon-reported complication rate. Addressing this discrepancy in perception will be imperative in the advancement of LKD. One way to allay potential donor fears is to counter them with data. Interestingly, 100% of LDs who reported complications also stated they would make the decision to donate again. The personal satisfaction of LKD appears to be more important than any self-reported complication. Educating potential donors with outcomes data may serve to assuage their fears and to encourage donation.

The time and cost commitment of presurgical evaluation, donation, recovery, and follow-up appointments can be daunting for potential donors. Despite the time commitment, only 1.2% of LDs who were out of work for 4 or more weeks indicated that they would not repeat their decision to donate. This fear of time spent away from work is likely related to the financial burden associated with lost income, which has been identified as a major deterrent of living organ donation.<sup>23</sup> Financial incentive for organ donation is a difficult topic surrounded by a great deal of ethical debate. Although the World Health Organization has banned payment for organs, some nations have allowed LDs to be

directly compensated (by individuals or government programs) as a means of increasing the number of available organs.<sup>24,25</sup> In the United States, there is no financial incentive for LDs. However, potential donors may not realize that the cost of medical care and time lost from work may be recouped through insurance reimbursement. Informational resources, such as web sites, may not specifically address individual potential donor circumstances. In such cases, a social worker may provide decision-changing information that can positively impact the potential donor's decision.

One limitation of our analysis is that our control group is not an ideal one. Had the CSs consisted of individuals excluded for HLA typing alone, the CS and LD groups would likely have displayed a more equivalent PCS. Additionally, this study was limited by the small sample size of the LD group, which consisted predominantly of whites. Including more than one transplantation center would incorporate a larger, more diverse population and would strengthen the validity of the data. Ideally, a national donor registry could be established to track this data on a wider scale.

Living kidney transplantation is a superior alternative to dialysis for individuals who are suffering from ESRD. This study indicates that LDs are physically and mentally healthier than the general population after LKD. The decision to donate is not one that can be taken lightly, and potential donors and transplantation programs should discuss the possibility of complications, financial and time commitments, and QOL after LKD. It is imperative that potential donors receive adequate information to make a well-informed decision about LKD. Studies such as this one suggest that LKD is a safe and satisfying experience.

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